



Understanding steroids

A guide for patients with a brain tumour

How can steroids help when you have a brain tumour?

When you have a brain tumour you can develop certain symptoms. These symptoms depend on the position of the tumour in the brain and may include weakness on one side of the body, memory problems or difficulty with speech and language. Symptoms are sometimes worse when there is **swelling** around the tumour. This swelling is called cerebral oedema.

Cerebral oedema is a collection of fluid in the brain tissue surrounding the tumour. It can also occur after any injury to brain tissue.

Tumours inside the skull are growing in a confined space. The tumour and cerebral oedema can create pressure inside the skull which may cause symptoms. Often the symptoms will be similar to the ones you had when the tumour was diagnosed.

Some people have headaches and nausea. This indicates that there may be some swelling around the tumour and pressure inside the skull.

Steroid medication reduces cerebral oedema and can improve symptoms.

What are steroids?

Steroids are naturally occurring hormones. The steroids produced by the body are called **corticosteroids** and their actions are very complex. They are produced in small quantities by the adrenal glands.

Your body controls the amount of natural corticosteroid it needs to function normally.

When you have cerebral oedema, the body needs more corticosteroid that can be produced naturally.

Your doctor may prescribe an artificial corticosteroid (steroid medication) to reduce the swelling around your tumour and improve your symptoms. Steroid medications do not treat the tumour.

The steroid medication most commonly prescribed to treat cerebral oedema is **dexamethasone**.

The steroids used to treat cerebral oedema are different from anabolic steroids which are used by some athletes to build muscle.

When will steroids be prescribed?

Steroids may be prescribed at different times:

- **When cerebral oedema is seen on your brain scan**
- **Around the time of surgery**
Cerebral oedema can occur at the time of surgery. Steroids may be prescribed before or after surgery. Your steroid dose may be reduced and stopped over a period of days as the swelling reduces after surgery.
- **Around the time of radiotherapy**
Radiotherapy treatment can cause cerebral oedema. Steroids may be prescribed during and/or after treatment.
- **Around the time of chemotherapy**
You may have chemotherapy as part of your initial treatment and/or at a later date if the tumour is growing.
- **Any time you have problems which are thought to be caused by cerebral oedema**

What are the side effects of steroids?

The side effects experienced vary from person to person. These are usually more noticeable when you are on a higher dose or when you have been taking steroids for a while.

Below is a list of the more common side effects with advice on how to cope with them.

- **Problems with sleeping**
To reduce the effects of difficulty sleeping (insomnia) take your tablets in the morning. If you are prescribed steroids twice a day, take them in the morning and early afternoon, no later than 3pm.
- **Increased appetite leading to weight gain**
You may have cravings for sweet food and an increased appetite. Try and keep to a healthy balanced diet, although some weight gain may be unavoidable. Information about healthy eating is available from Macmillan Cancer Support and from the cancer information centre at The Christie (department 7). Ask to see the dietitian if you are having difficulties managing your weight. Your appetite should return to normal after steroid treatment.
- **Changes in your mood**
Steroids can affect your mood. You may feel irritable, agitated, depressed or have mood swings. This should return to normal when the dose is reduced, or steroid treatment finishes. You may need additional help to deal with these effects. Discuss any concerns with your specialist nurse or doctor.
- **Irritation of the stomach lining**
You may experience heartburn or indigestion. Take your tablets with food or a glass of milk. We will prescribe additional medication to protect your stomach lining. Tell your specialist nurse or doctor if you are experiencing heartburn or indigestion.

- **Increased thirst and frequent urinating**

The body regulates sugar levels in the blood using insulin. Steroids can affect your blood sugar level, causing a type of diabetes to develop. The symptoms include increased thirst and passing urine more often. Tell your specialist nurse or doctor if this is happening to you. A simple urine test can detect changes in blood sugar level. It may be possible to control this by altering your diet. Ask for advice. Occasionally medication is needed to control the blood sugar. Blood sugar levels usually return to normal after steroid treatment finishes.

- **If you are diabetic your blood sugars may be affected**

You will need to monitor your blood sugars closely. Your doctor will make changes to your diabetic medication if needed.

- **Fluid retention**

If you experience fluid retention (puffiness or swelling) in your legs or a bloated feeling in your stomach, seek advice from your specialist nurse or doctor.

- **Muscle weakness in the upper arms and legs (thighs)**

You may notice that it is more difficult to perform daily activities such as climbing the stairs or getting out of a chair. The steroids cause this weakness. It is called 'proximal myopathy'. It is more likely to be a problem if you have been taking steroids for a number of weeks or months. A physiotherapist can advise you of the types of activity and exercises that can help in this situation.

- **Interruptions to the menstrual cycle**

Your menstrual cycle may become irregular. This usually returns to normal once steroid treatment has finished. It is not advisable to become pregnant when you are taking steroids. Please discuss any concerns regarding contraception or pregnancy with your specialist nurse or doctor.

- **Increased risk of infection and delayed healing**

Steroids can affect your immune system and increase your risk of infection such as oral thrush (fungal infection), urine infections and chest infections. Tell your specialist nurse or doctor if you have:

- a raised temperature
- flu-like symptoms
- delayed healing of cuts or wounds
- pain or stinging when passing urine
- persistent cough
- a sore mouth.

Avoid coming into contact with people who have a cold or other infection. Tell your specialist nurse or doctor if you think you have been exposed to shingles, measles or chicken pox - as you may need additional treatment.

- **Changes in the skin including bruising, stretch marks and acne**

The side effects of steroids can cause changes in your appearance. If this is causing you distress, talk to your specialist nurse. A referral for counselling may be useful.

- **Interaction with anti-seizure medication**

Anti-seizure medication and steroid medication are often used together, although this can sometimes affect the way the medications work. Your doctor will be monitoring you for any adverse interactions.

This list contains the more frequently occurring side effects. For additional information, please read the information leaflet provided with the medication and discuss with your pharmacist, doctor or specialist nurse.

Steroid doses

The aim of steroid treatment is to reduce the symptoms of cerebral oedema. Using a dose of steroids that will not give you too many side effects.

Steroids can be taken over a number of days, weeks or months. You may be prescribed a 'maintenance dose' or a 'reducing dose' of steroids.

Doses of dexamethasone usually vary between:

0.5 milligrams (mg) and 16mg per day

Tablets are available in two strengths:

0.5 mg (500 micrograms) and 2mg

Dexamethasone may be prescribed at different times of the day, for example, at breakfast and lunch time. This is called a 'divided dose'. Please take your dexamethasone with food or a glass of milk to reduce the risk of any gastric irritation.

Dexamethasone is usually taken in tablet form. It is also available as an injection or syrup.

Prednisolone is another steroid medication that is sometimes used to reduce cerebral oedema.

Steroid medication should never be stopped suddenly.

Gradually reducing the steroid dose over time prevents the body from reacting adversely to the withdrawal of artificial steroids.

Your doctor or specialist nurse will advise you about steroid reduction.

When should I ask for advice?

Whenever you have questions, concerns or symptoms.

Who can I ask for advice?

You can ask your specialist nurse, doctor, GP or pharmacist. A dietitian or physiotherapist can provide additional advice about managing side effects.

Please fill in the name and contact number of your:

Specialist nurse:

GP/hospital doctor:

Physiotherapy/dietitian:

Safety checklist:

- Never stop taking steroids suddenly.
- Make sure you do not run out of tablets.
- Carry your steroid card with you at all times.
- Tell your doctor, dentist, pharmacist and nurse that you have been treated with steroids.
- If you are not able to take your tablets due to sickness, tell your specialist nurse or doctor.

The chart in this booklet can be used to record your steroid dose. The effect of the steroids on your symptoms, and any side effects you may experience.

Please take this booklet with you to hospital and GP appointments.

For further information about steroids:

Cancer Help UK

www.cancerhelp.org.uk

Useful contact details:

Macmillan Cancer Support

Tel: 0808 808 0000

www.macmillan.org.uk

The British Brain and Spine Foundation

Tel: 0808 808 1000

www.bbsf.org.uk

The cancer information centre at The Christie (department 7)

Tel: 0161 440 8100 or 8107

Date:	Medication: <i>Dexamethasone</i> Dose & Time:	Symptoms: How are you feeling?	Side effects:	Comments or instructions:	Discussed with:
Example: 17th Sept	2mg in the morning	Morning headache. Worsening right arm weakness.	Feeling very hungry.	Increase dose to 4mg	GP Review: 1 week
					Review:

Date:	Medication: Dexamethasone Dose & Time	Symptoms: How are you feeling?	Side effects:	Comments or instructions:	Discussed with:
					Review:
					Review

This leaflet was written by The Association of Neuro-oncology Nurses (ANON)

We try to ensure that all our information given to patients is accurate, balanced and based on the most up-to-date scientific evidence. If you would like to have details about the sources used please contact **patient.information@christie.nhs.uk**

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For more information about The Christie and our services, please visit **www.christie.nhs.uk** or visit the cancer information centre at Withington, Oldham or Salford.

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